

# Spina Bifida Diagnosis Experiences in Michigan (January 2006 or after)

PLEASE READ THOROUGHLY BEFORE CONTINUING.

## SURVEY PARTICIPANTS:

This survey is directed at mothers and fathers who received the DIAGNOSIS of spina bifida for their child, prenatally or postnatally during or since January of 2006. The diagnosis should have been made in the state of Michigan. The manner and timing of closure (postnatal closure or fetal surgery) are NOT considerations in the survey. The survey seeks information about the information and experience during the DIAGNOSIS of spina bifida.

## BACKGROUND:

Anecdotally, many parents share their spina bifida diagnosis stories. Michigan HB 5098 of 2015 ([http://www.legislature.mi.gov/\(S\(2wv1sk3v2sofmsn2u2le3y41\)\)/mileg.aspx?page=getobject&objectname=2015-HB-5098](http://www.legislature.mi.gov/(S(2wv1sk3v2sofmsn2u2le3y41))/mileg.aspx?page=getobject&objectname=2015-HB-5098)), a non-partisan pro-information bill assigned to the House Committee on Health Policy, aims to provide families with timely, complete, up-to-date information on treatment options and outcomes for babies diagnosed with spina bifida.

## SURVEY PURPOSE:

The Spina Bifida Association of Michigan (<http://sbaofmi.org/>) aims to collect diagnosis stories to collect evidence for the current (last ten years) need and importance of passing Michigan HB 5098 of 2015. Neither the Michigan House of Representative nor the Michigan House Committee on Health Policy are involved in the administration of this survey.



**DURATION:**

This survey will take most participants five (5) to fifteen (15) minutes to complete, depending on the depth of information submitted, complexity of diagnosis scenario, and typing speed.

**COMPENSATION:**

Your participation in this survey is entirely voluntary. No participant, researcher, medical care provider, or politician in connection with the survey or HB 5098 will be compensated in any way due to your participation in the survey. None of the submissions will be sold for profit.

**CONFIDENTIALITY:**

Your user ID will not be collected. You will be asked to submit your name and email address. These questions are optional and will only be used for clarifying questions from the researchers or to update you as to the progress of HB 5098. Anything you submit in OTHER fields of this form may be shared publically to support the importance of the bill.

**ACCUSATIONS:** Specific names of care providers and facilities will be REDACTED as the focus of this survey and of HB 5098 is to support healthcare providers and facilities with information rather than accuse and degrade anyone or any entity.

**TIMEFRAME:** As HB 5098 is in committee as of the release of this survey, the survey may be extended or shortened. This survey will remain available at least until March 15, 2016 unless otherwise communicated five (5) days in advance.

\* Required

**Full Name**

Full name of survey participant. This should be the parent who received his/her child's diagnosis of spina bifida during or since January of 2006. This question is optional and will only be used for clarifying questions from the researchers or to update the participant as to the progress of HB 5098.

Your answer

**Email Address**

This question is optional and will only be used for clarifying questions from the researchers or to update the participant as to the progress of HB 5098.

Your answer

### Date of Initial Diagnosis \*

Please provide the date your child was INITIALLY diagnosed with spina bifida. If you are not sure, please choose the closest date possible.

Date

mm/dd/yyyy

### County of Initial Diagnosis \*

The county (NOT CITY) of INITIAL diagnosis should be a Michigan county. (Example: Ingham)

Your answer

### Care Professional of Initial Diagnosis \*

Who rendered/communicated the INITIAL diagnosis? If more than one care professional was present for the conversation, please check multiple options.

☐ Doula

☐ Family Physician

☐ Genetic Counselor

☐ Maternal Fetal Medicine Specialist (MFM)

☐ Neurosurgeon

- ☐ Pre-natal closure (Fetal surgery)
- ☐ Termination
- ☐ Any of the above in conjunction with adoption
- ☐ None was emphasized over another.
- ☐ Other:

### Life Expectancy \*

At the meeting at which you received your INITIAL diagnosis, if you received information (verbal or in print form) regarding your child's life expectancy, what was it? If you did not receive information regarding life expectancy, type NONE. If you are not sure, type NOT SURE.

Your answer

### Physical and/or Functional Outcomes \*

At the meeting at which you received your INITIAL diagnosis, if you received information (verbal or in print form) regarding physical and/or functional (movement, sensation, paralysis, ambulation, independence, etc.) outcomes associated with spina bifida, what was it? If you did not receive information regarding physical and/or functional outcomes, type NONE. If you are not sure, type NOT SURE.

Your answer

### Educational and/or Intellectual Outcomes \*

At the meeting at which you received your INITIAL diagnosis, if you received information (verbal or in print form) regarding educational and/or intellectual (grades, IQ, learning disabilities, graduation,

schooning, etc.) outcomes associated with spina bifida, what was it? If you did not receive information regarding educational and/or intellectual outcomes, type NONE. If you are not sure, type NOT SURE.

Your answer

## Psychosocial Outcomes \*

At the meeting at which you received your INITIAL diagnosis, if you received information (verbal or in print form) regarding psychosocial (mental health, well-being, interaction with other people, independence, etc.) outcomes associated with spina bifida, what was it? If you did not receive information regarding psychosocial outcomes, type NONE. If you are not sure, type NOT SURE.

Your answer

## Support Contacts \*

During the meeting at which you received the INITIAL diagnosis, were you provided any of the following? Check all that apply. If you were not provided any of this information, leave this question blank.

- ☐ Contact information regarding support programs and services for parents of children with spina bifida.
- ☐ Information hotline specific to spina bifida
- ☐ Contact information for a spina bifida resource center
- ☐ Contacts or website for national and/or local spina bifida organizations
- ☐ Contact for other parents of children with spina bifida
- ☐ None of these

☐ Other



## Additional Information

Please share any other information that would allow the researchers to better understand your diagnosis experience. Include any pertinent information not already included above. (This question is optional).

Your answer

Thank you for your participation. Please submit survey below.

SUBMIT

100%: You made it.

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☐ Nurse Midwife☐ Obstetrician/Gynecologist (OB/GYN)☐ Radiologist☐ Ultrasound Technician☐ Other:

### Treatment Options \*

Which treatment options were mentioned/discussed/provided to you in printed form during the meeting at which you received the INITIAL diagnosis? Check all that apply.

☐ Post-natal closure☐ Pre-natal closure (Fetal surgery)☐ Termination☐ Any of the above in conjunction with adoption☐ None☐ Other:

### Treatment Emphasis \*

Of these treatment options, which options/treatments were recommended or emphasized above others?

☐ Post-natal closure